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be Still

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Post-Celebration Celebration

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Cover Page Footnote

Katherine Taylor would like to thank her daughters, Aleena and Zahra, for their unending love and imagination. She would like to thank her husband and her in-laws for their support. She would like to thank her Mom for always being there when she needs her.

We experienced a lot in the NICU. It was very, very trying. Getting to the point where we could coordinate our bottle squeezes with the swallowing pattern of a newborn with a cleft palate was not something that we expected to have to do as new parents.

Many parents were not able (either financially or perhaps mentally) to be there with their babies. That was even harder to see. But the nurses are there, doing the best that they can. And sometimes there are volunteers that come to hold and talk to the babies that are healthy enough.

Childbirth is supposed to be such a happy time. The staff try to keep your hopes up as best they can, but being in this space and situation was still thoroughly tough. I hope you are all able to find some stillness and some thankfulness in whatever spaces you are currently in, even if they are not quite what you had imagined.

ARTIST STATEMENT: KATHERINE TAYLOR

- *I would like to thank my daughters, Aleena and Zahra, for their unending love and imagination. I would like to thank my husband and my in-laws for their support. I would like to thank my Mom for always being there when I need her.*

Post-Celebration Celebration

Our first daughter, Aleena, was born in Celebration.

Her name means noble, fair, light, and proud.

I met her on my chest, for only a second.

Her cries were not sufficiently loud.

They whisked her away; a pediatrician came.

Her air-permeating words soon filled the room.

She said, “Aleena may have a syndrome. She has a cleft palate. And her jaw is unusually small.”

My daughter has a syndrome? What kind of syndrome? I could not comprehend this at all.

They needed to move her, where they could take better care.

I next saw her in an industrial cart.

Shipped with a face-engulfing, pressurized oxygen mask.

Along with a large piece of my heart.

Our celebrations of heading home were dashed, delayed.

Overnight, both her lungs had collapsed.

She was transferred again. Oh, can't we just win?

At least my doctor was able to let me out of my own hospital trap.

We arrived early next morning to see our new babe.

Sleep-deprived, frazzled, bewildered, nerves unbearably thin.

A shift change. Of course. My tears came with force.

They were not yet able to let us come in.

Her only hope was a machine that would give oxygen to her blood

To give her lungs time to recover, to reset.

She was at her third hospital in her first days of life.

She hadn't even reached the 48 hour mark yet.

We had to make the decision to try this machine.
In a stark conference room we sat.
We learned of the dangers of possible strokes and clotting and bleeding.
But we asked them to start the machine right away---STAT.

Extrocorporeal Membrane Oxygenation---ECMO.
That is what kept her alive for 4 grueling days.
The first time we saw her, in this third hospital
She was enveloped in a cyanotic blue haze.

There were so many helpers, my husband, relatives, friends, the nurses,
a social worker, and physicians.
They all tasked me with pumping my “liquid gold milk.”
I could do nothing else under those trying conditions.
It is the only thing I could do to help.

She had 3 or 4 baby roommates in her less critical, shared hospital room.

They cycled in and out, one by one, there was a girl with a giant pink head bow.

But her first roommate was a boy. Adopted. Austin bound. What a joy.

After each, I felt guilty, wondering how many more days were left for us now?

We were waiting for her eating to improve.

We wanted so much for her to eat feeding tube-free.

We wanted so much for her to finally be home.

We were tired of being a party of two and not three.

We stuck it out there for 56 days and 56 long, lonely nights.

My husband and I would alternate “good” days and “bad.”

We were constantly thinking of her when we were not there.

What an absolutely tumultuous time that we had.

Then, it was finally time to celebrate!

But wait, not yet, not too soon.

The night before discharge, she started to snore.

And alarms quickly filled her room.

Her oxygen had dropped, her airway not protected.

The hospital “gifted” us an oxygen tank.

Along with her feeding tube, special bottles, an alarm of our own.

It would have been easier to transport loot from a bank.

Her outpatient specialist appointments were weekly.

Everything but her brain and heart were followed, monitored, and inspected.

Couple that with feeding, tube care, worry when the apnea alarm chimed a beware.

My own health was very neglected.

But that is the role of a parent.
To give your child everything that you've got.
I even weaned her off her tube at 1 years old.
I did not want her to be a tube-using tot.

I would gladly do it again if needed.
It took me 7 years to be able to say this simple thought.
Hormones make you forget some of the pain of childbirth.
Time makes you more willing to strive than to not.

This rhyme is imperfect, just like life's course.
You're set, then you get sidetracked again.
We're safe and home for now; no oxygen or apnea or tubes.
In celebration, we say ***Ameen.***

I grew up in a small mountain town in Colorado. I have always loved writing creatively and more recently found the field of medical humanities. Whichever specialty I choose to practice in as a D.O., I will try to include writing, reading, and sharing patient and physician experiences in some form. I am a first year Osteopathic Medical Student at NSU. I am blessed with a wonderful family and blessed that I can continue to learn, grow, and find my own path. I am a wife and a parent, a student and a professional, and it can be difficult to navigate all of these daily and over the years. I only hope to build on what has past and be in awe of what will come in the future.

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